2nd REPORT OF THE MALAYSIAN REGISTRY of RENAL BIOPSY 2008

Sponsors:
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The National Renal Registry is funded with grants from:
The Ministry of Health Malaysia
AIN Medicare
Baxter Healthcare
Fresenius Medical Care
Roche

December 2008

ISSN 1985-6989

Published by:

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Cover illustration complimentary of Dr. Nik Hasimah Nik Yahya, HKL

Important information:

Rosnawati Yahya, Wan Jazilah W I (Eds) Second Report of the Malaysian Registry of Renal Biopsy 2008 Kuala Lumpur 2010.

This report is also published electronically on these websites http://www.msn.org.my/nrr or https://www.macr.org.my/emrrb .

ACKNOWLEDGEMENTS

The National Renal Registry would like to thank the following:

All the nephrologists and staff of the participating hospitals
For their hard work and contribution,

The Ministry of Health, Malaysia
for support seen and unseen,

For their generous support: -

AIN Medicare
Baxter Healthcare
Fresenius Medical Care
Roche

The staff of the Clinical Research Centre

&

All who have in one way or another supported the National Renal Registry.

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ABOUT MALAYSIAN REGISTRY OF RENAL BIOPSY

Renal biopsy remains the main investigation in the diagnosis of renal diseases. In addition, it plays a major role in determining the management and prognosis of parenchymal renal disease. The collection of demographic, clinical and laboratory data at the time of biopsy and the set up of a database are useful tools for studying renal parenchymal diseases.

The development of a renal biopsy registry in each country promotes many advantages and these include comparison in incidence of renal diseases, identification of different policies and practices in renal biopsy in different areas, linkage with other registries such as dialysis or transplant registry and identification of rare renal diseases. Thus, the registry is a source of epidemiological data and would provide useful information in the planning of health care and in organizing prospective clinical studies.

The incidence of glomerular disease varies according to population, demographic characteristics, environmental factors, socio-economic status and the prevalence of infectious diseases. At present, there is limited information on the prevalence and incidence of glomerular disease, its potential disease burden and the temporal trend in Malaysia. Hence, the Malaysian Registry of Renal Biopsy (MRRB) was set up in 2005 to address this deficiency.

The MRRB collects information about patients who undergo renal biopsy in Malaysia. The MRRB is a new component of National Renal Registry (NRR), which has been operating the Malaysian Dialysis and Transplant Registry (MDTR) since 1993.

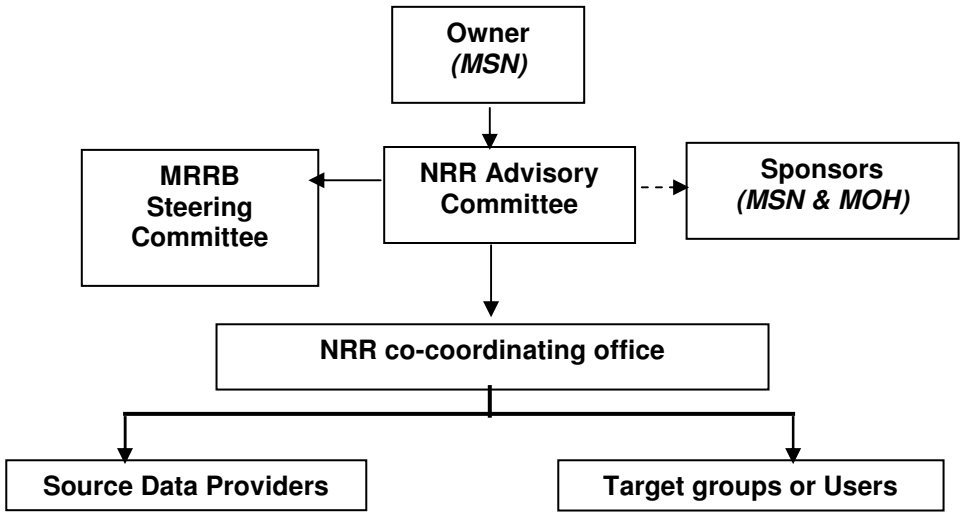
Objectives

The objectives of the MRRB registry are to:

1. Determine the disease burden attributable to glomerular disease (GD) by quantifying its incidence and prevalence, and its geographic and temporal trends in Malaysia.
2. Identify subgroups in the population at high risk of GD to whom preventive efforts should be targeted.
3. Identify potential causal and risk factors involved in GD.
4. Describe the clinical presentation and spectrum of GD.
5. Stimulate and facilitate basic, clinical and epidemiological research on GD.
6. Identify causes of allograft failure in our renal transplant population.
7. To audit the renal biopsy procedure, monitor both complications and quality of specimens in addition to identifying risk factors associated with complications.

Organization

The NRR organization is as follows:



Owner

The Malaysian Society of Nephrology (MSN) is the owner of this registry.

Sponsors

The MRRB is sponsored by the Malaysian Society of Nephrology (MSN) and the Ministry of Health, Malaysia.

NRR Advisory Committee

This is the committee established by the sponsors. The NRR Advisory Committee's role is to ensure that the MRRB stay focused on its objectives and to assure its continuing relevance and justification.

MRRB Steering Committee

The MRRB Working Committee supervises its operations.

National Renal Registry office

The NRR coordinating office is the designated coordinating center. It coordinates the data collection among the Source Data Providers (SDPs). It collaborates with Clinical Research Centre of Hospital Kuala Lumpur that provides epidemiological and statistical support for MRRB.

Source Data Providers (SDP)

These are centres that contribute the required data for MRRB. The SDP collects and enters data directly through the on-line web-base system. The pilot phase of the registry consists of SDPs from Ministry of Health.

Throughout this initial phase, we have refined and improved the database. In 2008, the registry is expanding to a national level to include participation from all nephrologists and renal physicians in Malaysia who perform renal biopsies. We hope the nephrology community will support us by submitting information, which is crucial to eventually improve the management of patients with Chronic Kidney Disease (CKD).

To participate in MRRB

Centres interested to participate in this registry please write in to NRR officially via post or email nrr@msn.org.my.

The following documents need to be completed and returned to facilitate participation.

- Centre Participation Self Reply Form
- Authorization Form
- Information Security Policy/User Agreement . One form per nominee as listed in the Authorization form. Users must have a personal mobile phone to received SMS authentication.

Upon receiving these documents, the centre shall be registered and each of the users of the MRRB shall be notified via their e-mail address.

Methodology

All patients from participating centres who undergo any kidney biopsy (native or graft) are to be enrolled into the registry.

On-line data submission is through MRRB web application or paper CRF. The data variables collected include demography, clinical presentation, and indication of biopsy, renal function, and laboratory data at presentation and at the time of biopsy, serological markers, virology status and histopathological result. In addition, an update on outcomes in terms of significant end-points such as end stage renal disease or death will be recorded annually.

DATA CONTRIBUTING CENTRES FOR THIS REPORT

Centre Name	Adult Nephrology	Paediatric Nephrology
96 Hospital Angkatan Tentera Lumut	√	
Fan Medical Renal Clinic	√	
Ipoh Specialist Hospital	√	
KPJ Ampang Puteri Specialist Hospital	√	
KPJ Selangor Specialist Hospital, Shah Alam	√	
Kuala Lumpur Hospital	√	√
Lam Wah Ee Hospital, Pulau Pinang	√	
Likas Hospital		√
Melaka Hospital	√	
Metro Specialist Hospital, Sungai Petani	√	
Normah Medical Specialist Centre, Kuching	√	
Pulau Pinang Hospital	√	√
Queen Elizabeth Hospital, Kota Kinabalu	√	
Raja Perempuan Zainab II Hospital, Kota Bharu	√	
Raja Permaisuri Bainun Hospital, Ipoh	√	
Sarawak General Hospital, Kuching	√	
Selayang Hospital	√	√
Serdang Hospital	√	
Sultan Ismail Hospital, Pandan		√
Sultanah Aminah Hospital, Johor Bharu	√	
Sultanah Bahiyah Hospital, Alor Star	√	
Sultanah Nur Zahirah Hospital, Kuala Terengganu	√	
Sunway Medical Centre	√	
Tengku Ampuan Afzan Hospital, Kuantan	√	√
Tengku Ampuan Rahimah Hospital, Kelang	√	
Tuanku Ja'afar Hospital, Seremban	√	√
Tung Shin Hospital, Kuala Lumpur	√	
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Report Editors
Rosnawati Yahya
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FOREWORD

FOREWORD

The second report of the Malaysian Registry of Renal Biopsy (MRRB) showed an increase in the number of centers reporting. This is gratifying especially as most of the new centers were form the Universities and the private sector. The first report was confined to centers from the Ministry of Health only. The addition of data from the new centers will hopefully give a more “national” representation of the pattern of glomerular diseases in the country. The ascertainment rate, however, has dropped in 2008 to 76%. Of the 1519 biopsies that were done, 1155 were reported. This is unfortunate as a large segment of useful information is missing. It is hoped that nephrologists will take some time off their busy schedule to report on the biopsies they did.

The pattern of primary and secondary glomerular diseases was similar to that seen in the first report. Any change in pattern in the short term is more likely to be the result of more centers reporting (eg more pediatric nephrology centers) or more biopsies being done than any real change in incidence of glomerular diseases. Facilities for doing renal biopsies are now available in all major hospitals in the country. However indications for biopsies may vary between practitioners and this to some extent affects the pattern observed. Thus the real “pattern” can only be seen after the registry has matured and achieve a high ascertainment rate and there is some consistency amongst practitioners on the indications for biopsy. Nephrotic syndrome remained the most common indication for doing renal biopsy in 2008 followed by asymptomatic urinary abnormalities.

Data from registries serve not only to indicate incidence/prevalence and clinical presentation of diseases but more importantly help guide clinical practice. Data from the Malaysian Dialysis and Transplant Registry (MDTR) have helped in the formulation of clinical practice guidelines on Renal Replacement Therapy in Malaysia along with results from clinical trials. It is hoped that with information accumulated in the MRRB, we could one day develop some practice guidelines on the management of glomerular disease. The registry will have to look at means of collecting more clinical data on outcome such as renal survival, complications of glomerular disease etc before we can embark on such a task.

This year (2010) the funding for all registries by the Ministry of Health has been drastically reduced putting the long-term viability of many registries in peril. The National Renal Registry is seriously looking at measures to reduce costs and also to look for additional sources of income. It will endeavour to maintain all existing registries under its purview.

Dr Zaki Morad
Chairman, National Renal Registry

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REPORT SUMMARY

CHAPTER 1: OVERVIEW OF RENAL BIOPSY IN MALAYSIA

The second MRRB report included data from MOH centers as well as from universities and private hospitals. Universities and private hospitals contributed data to MRRB from 2008.

- Total of 33 centers contributed data in 2008. There were an additional 11 new centers.
- The first report was exclusively from 23 MOH centers only.
- Renal biopsies performed in MOH centers from 2005-2008 was also updated.
- 1519 renal biopsies were performed in 2008 and of these, 1155 were reported.
- The ascertainment rate was 92.2%, 91.05 %, 92.9% and 76.03% for the years 2005, 2006, 2007 and 2008 respectively.
- Average ascertainment rate for the years 2005 – 2008 was 86.5%.
- 89.4 % of renal biopsies in 2008 were reported in native biopsies.
- 83% of native biopsies were done in patients older than 15 years old and in this group 91.8% of the biopsies were done in patients less than 55 years of age.
- There were more females than males (ratio 3:2) due to the higher number of females amongst patients biopsied for lupus nephritis.
- 869 (23%) of the biopsies from 2005 to 2008 yielded less than 10 glomeruli.
- 38 (1%) of biopsies were classified as missing. The histopathological reports were not submitted to MRRB.
- 47.6% histopathology slides were read by pathologists in the same hospital and 52.4 % were sent to be read by pathologists in another hospital.
- Main indications for native kidney biopsies were nephrotic syndrome (46%) and urinary abnormalities (28%).
- 54 % had normal renal function and 32% had impaired renal function. Data was missing for 14%.

CHAPTER 2: PRIMARY GLOMERULONEPHRITIS

The commonest primary GN reported was Minimal Change Disease (MCD) followed by Focal Segmental Glomerulosclerosis (FSGS).

Minimal change disease

- Accounted for 33% of total primary GN
- Mean age at the time of biopsy was 29.1 ± 12.8 years.
- Male to female ratio was 2:1.
- Nephrotic syndrome was the most common clinical presentation.
- Twenty percent had e-GFR < 60 ml/min/1.73 m2 at time of biopsy
- There was a higher risk of renal impairment with increasing age.

Focal Segmental Glomerulosclerosis (FSGS)

- Accounted for 30% of total primary GN.
- Mean age at the time of biopsy was 32.5 ± 13.5 years.
- Male to female ratio was 1.3:1.
- Nephrotic syndrome was the most common clinical presentation.
- Forty-one percent had e-GFR < 60 ml/min/1.73 m2 at time of biopsy
- There was a higher risk of renal impairment with increasing age

Idiopathic Membranous Nephropathy (IMN)

- Accounted for 11% of total primary GN.
- Mean age at the time of biopsy was 45.3 + 14.7 years.
- Male to female ratio was 1.3:1.
- Nephrotic syndrome was the most common clinical presentation.
- Thirty-seven percent had e-GFR < 60 ml/min/1.73 m2 at time of biopsy.
- There was a higher risk of renal impairment with increasing age

IgA nephropathy

- Accounted for 19% of total primary GN.
- Mean age at the time of biopsy was 33.8 ± 12.5 years.
- Male to female ratio was 0.9:1.
- Asymptomatic urine abnormalities was the most common clinical presentation, followed by nephritic syndrome.
- Forty-six percent had e-GFR < 60 ml/min/1.73 m2 at time of biopsy.
- Males tend to have worse renal function at presentation compared to females.

CHAPTER 3: SECONDARY GLOMERULONEPHRITIS

The commonest secondary GN reported was lupus nephritis. Diabetic nephropathy was the second commonest glomerular disease reported.

Lupus nephritis

- Accounted for 86% of total secondary GN.
- Mean age at the time of biopsy in adult lupus nephritis was 30.3 ± 10.4 years.
- Male to female ratio was 6.9:1.
- Urine abnormality (38%) was the commonest clinical presentation followed by nephrotic syndrome (30%).
- The commonest histopathological finding was WHO or ISN/RPS class IV or IV+V (59%).
- There was no clear correlation between histopathological findings and clinical presentation. However, class IV or class IV+V were more likely to present with symptomatic renal disease.
- The prevalence of hypertension was higher in class IV or class IV +V
- The prevalence of impaired kidney function correlated with histopathological findings. Class IV was more likely to have impaired renal function.
- About 2/3 of cases with lupus nephritis fulfilled 4 or more American Rheumatological Association (ARA) criteria at presentation.
- Fulfilling the ARA criteria does not predict the severity of renal lesion.

CHAPTER 4: PAEDIATRIC RENAL BIOPSY

This chapter reports on renal biopsy in children less than 15 years of age and the summary details the report for the years 1999 -2008.

- 809 renal biopsies were performed in 755 children.
- Majority of biopsies were performed in MOH hospitals.
- 770 (95.2%) were assessed to be adequate. The success rate is comparable to reports from Thailand, UK and Japan.
- 621(77.2%) yielded more than 10 glomeruli.
- 51.9% were performed in girls.
- Nephrotic syndrome (52.9%) was the most frequent clinical presentation.41.8% of the diagnosis on biopsy was FSGS and minimal change disease in 28.7%.
- The commonest biopsy finding for nephritic syndrome was post-infectious glomerulonephritis (36.3%).
- Overall, in terms of diagnosis on biopsies for the paediatric age group, lupus nephritis was the commonest finding in 24.8%, followed closely by FSGS (24.6%) and MCD accounted for 17.27%.
- There were no difference in terms of age at presentation, race, gender, urine albumin excretion and creatinine clearance in children with FSGS and minimal change disease at biopsy.
- There was no difference in patient survival for FSGS and minimal change disease.
- There was however definite poorer renal survival, 92.4 % and 84.6% at 3 and 5 years for the FSGS group. Renal survival for the MCD group was at 95.9% at both 3 and 5 years.
- Commonest biopsy finding for the lupus group was class IV and Class V + IV (64.2%)
- Renal survival for the lupus group was 97.1 % at both 3 and 5 years.
- The complication rate for renal biopsy was 5.4%. The most common complication was bleeding which occurred in 4.1 %.

CHAPTER 5: RENAL ALLOGRAFT BIOPSY

This chapter reports on renal allograft biopsy and the summary details the report for the years 2004 - 2008.

- The number of renal allograft biopsies doubled over the last 5 years despite a decreased in the number of new transplant recipients.
- This was largely contributed by an increase in participating centres reporting to MRRB.
- 90% of renal allograft biopsies were performed in 5 centers in Klang valley.
- The biopsies were usually performed in the age group 15 to 54 years.
- Acute and chronic allograft dysfunction was the commonest indications.
- Chronic allograft dysfunction has assumed more importance in recent years. This was supported by a 5 fold increase in renal biopsies performed for this reason. (10 % in 2004 to 47% in 2008)
- In addition, there was a marked increase in the number of renal allograft biopsies performed after one year post transplant. (35% in 2004 and 55% in 2008)
- 96% of biopsies were performed under real time ultrasound guidance.
- 97% of biopsies were not associated with any complications.
- The histological diagnosis on biopsy in order of importance was acute rejection (49%), acute tubular necrosis (16%) calcineurin inhibitor toxicity (15%) and chronic allograft nephropathy. (15%)